The psychosocial effects of living with type 1 diabetes
- a literature review

De psykosociala effekterna av att leva med typ 1 diabetes
- en litteraturstudie

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Introduction: Diabetes mellitus is an incurable, widespread disease increasing globally. 2017 there were 425 million people with the diagnosis, and circa 10% of these have type 1 diabetes mellitus. Diabetes mellitus is a disease which requires a lot of self-management. Living with a chronic disease may impact the patient’s mental and psychosocial health.

Aim: The aim of this literature review was to describe how living with type 1 diabetes mellitus may affect the patient’s psychosocial health.

Method: The study was conducted as a literature review using Polit and Beck’s (2017) nine steps. Data was collected using two databases, PubMed and CINAHL. The articles chosen were critiqued according to Polit and Beck’s (2017, p. 102-109) “Guide to an Overall Critique of a Qualitative Research Report” and “Guide to an Overall Critique of a Quantitative Research Report”. Twelve articles in total were chosen for the result, six quantitative and six qualitative.

Results: Two main themes and seven subthemes were developed based on the results.

Conclusion: Healthcare professionals did not take these patients’ psychosocial health into consideration. Many patients also felt that they could not self-manage their disease in public due to others’ perception of them. This could result in complications.
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1. Introduction
Diabetes mellitus is an incurable, widespread disease, with an increasing prevalence in the global population. On a global scale, there are 425 million (2017) people with the diagnosis, with an estimation of the number rising to 629 million by the year 2045 (International Diabetes Federation, 2017a). In 2017, approximately four million people with diabetes died due to the disease and its complications globally (International Diabetes Federation, 2017b). In Sweden, approximately five percent of the adult population have been diagnosed with diabetes mellitus (Socialstyrelsen, 2018).

2. Background:
2.1 Diabetes mellitus
Diabetes mellitus is a condition in which the body suffers from insulin deficiency. The deficit of insulin results in elevated blood glucose. Instances of diabetes mellitus have been described as early as in ancient Egypt. The word diabetes originates from the Greek word for “go through”, and mellitus originates from the Latin word meaning “sweet”. Therefore, diabetes mellitus can be defined as increasing units of urine containing glucose (Mulder, 2012). Diabetes mellitus can be divided into multiple subsets, where type 1 diabetes mellitus [T1DM] and type 2 diabetes mellitus [T2DM] are the most common. Approximately 90 percent of those with diabetes mellitus are diagnosed with T2DM, while circa 10 percent are diagnosed with T1DM (International Diabetes Federation, 2017a).

Typical symptoms of T1DM include increased thirst, urination and hunger, as well as loss of weight. These symptoms can be present for approximately less than a month to sometimes several months. When the patient is displaying any of the aforementioned symptoms the potential T1DM diagnosis is confirmed by conducting laboratory tests consisting of blood glucose concentration which is above 11.1 mmol/L or when fasting above 7.0 mmol/L.

T2DM is characterised by the body not being able to metabolise glucose efficiently, which also leads to elevated levels of glucose in the blood. T2DM can in most cases be treated using diet and exercise, medication, and sometimes insulin therapy is eventually required. T2DM is most commonly diagnosed in geriatric and/or overweight patients. However, young and otherwise healthy people can also be diagnosed with T2DM (Mulder, 2012).

This literature review will focus strictly on T1DM.

2.2 Pathophysiology
T1DM and T2DM have different catalysts and should not be confused with one another. They are both chronic diseases, but T1DM occurs commonly among younger patients, although it can occur at any age. No one knows the exact cause behind the development of T1DM in patients. The immune system has a substantial role in the development of T1DM since the lack of insulin is a result of β-cell deficiency, destroyed by the body’s immune system. Without insulin, the body is unable to convert glucose into energy (Mulder 2012). Insulin is a hormone which is produced in the β-cells of the islets of Langerhans in the pancreas. The insulin helps the glucose in the blood to penetrate the cell membrane, where the glucose is then converted into energy (Veccio et al. 2018).

2.3 Complications
Even though it is possible to live a somewhat normal life with T1DM as a result of continuous advancements in diabetes treatment, many of those with T1DM still develop complications due to how the disease affects the body (International Diabetes Federation 2017b).
Short term complications caused by T1DM are hypoglycaemia and hyperglycaemia. Hypoglycaemia means that the glucose level in the blood is too low. Some examples of symptoms of hypoglycaemia are hunger, shaking, anxiety, disorientation, seizures, and coma. If a severe hypoglycaemic episode is left untreated, it can lead to death (Briscoe & Davis 2006). Hyperglycaemia means that the level of glucose in the blood is too high. Symptoms related to hyperglycaemia are for example headaches, increased thirst, frequent micturition, nausea, and vomiting. If the patient does not receive insulin the hyperglycaemia can develop into a diabetic ketoacidosis, which can result in a coma or death (International Diabetes Federation 2017a). It is therefore important to diagnose the patient as quickly as possible due to the increased risk of mortality that is connected to diabetic ketoacidosis (Cooke & Plotnick 2008).

Long term complications associated with T1DM include retinopathy, neuropathy, nephropathy, as well as cardiovascular diseases. Retinopathy means that fluid leaks from the blood vessels into the retina of the eye. This damage to the retina can cause impaired vision or even blindness (Acharya et al. 2008). Neuropathy is a type of nerve damage which can cause pain and numbness to the affected areas, primarily feet (International Diabetes Federation 2017b). Nephropathy is an injury to the capillaries and the glomerulus of the kidneys caused by elevated blood glucose levels (Yigit & Taskapan 2016). Cardiovascular disease means that the heart and/or blood vessels have been compromised (International Diabetes Federation 2017b).

2.4 Treatment and monitoring
T1DM requires insulin treatment. Insulin is injected into the subcutaneous tissue located on the stomach and/or thigh. This can be achieved through the use of a syringe, or an insulin pump. When using regular syringes, the patient has a long acting insulin as well as a rapid acting insulin. The long acting insulin acts as the basal need that the body has in order to keep the blood glucose stable throughout the day. This is normally injected one to two times a day. When eating or when the blood glucose level is elevated, rapid acting insulin is injected to lower and/or prevent temporary spikes in the blood glucose (Marvicsin et al. 2017).

Diet and exercise are two other factors which can impact the blood glucose level, this means that the patient needs to adjust their insulin doses accordingly. A way of doing this when it comes to food intake, is by counting carbohydrates and then injecting the appropriate insulin dose depending on how many carbohydrates the food contains (Vaz et al. 2018). Exercise increases the body’s insulin sensitivity, which can help the patient to maintain a stable blood glucose level and lower their insulin doses (Goldobin & Shorikova 2018).

Another form of treating T1DM is through the use of an insulin pump. The pump is a small device approximately the size of a mobile phone, which makes it possible for the patient to keep it in the pockets of their trousers. The insulin pump provides a continuous administration of rapid acting insulin through a tubing set which is attached to a needle that is placed on the skin, usually in the stomach area. The rapid acting insulin used in the pump is used both as basal insulin as well as to prevent spikes in blood glucose and to correct high blood glucose levels (Marvicsin et al. 2017).

In order to provide accurate insulin therapy, it is essential to monitor the blood glucose level (Marvicsin et al. 2017). This is achieved by utilising a blood glucose monitor, which is a device used to measure the concentration of glucose in the capillaries. Another way of monitoring the glucose level is by using a Continuous Glucose Monitor [CGM] which continuously measures the glucose level in the extracellular fluid, meaning that the level measured is not as accurate as a traditional blood glucose monitor. The CGM is placed under the skin and attached to a sensor which transmits signals to a receiver that displays the glucose level. For the CGM to function properly, it is necessary to calibrate it using a traditional glucose monitor. Another
form of glucose monitoring follows the same concept as a CGM, except that instead of continuously measuring the glucose level, the patients must swipe their device over the sensor, this is referred to as Flash Glucose Monitoring [FGM] (Marvicsin et al. 2017).

HbA1c is a test which can be administered to determine the glycaemic control in the patient for the last 90-120 days. This test is administered in conjunction with upcoming healthcare appointments. A high HbA1c indicates that the patient’s blood glucose level has for the most time been elevated for the past few months, and vice versa (Kaur et al. 2019). There is continuous technological progress being made in the area of diabetes treatment and monitoring, however living with T1DM still requires a lot of work on the patient’s part for their treatment to work effectively (Marvicsin et al. 2017).

2.5 Nurses’ role
Nurses are required to give their patients the best quality care and are constantly introduced to complex situations and are encountered by ethical challenges in their profession. To guide nurses in their fundamental practice there exists a Code of Ethics, where there are both international and national guidelines. National guidelines for nurses can be beneficial as they will also conform to the culture of the specific country (Zahedi, et al 2013). The Swedish code of ethics are translated from the International Code of Ethics [ICN] and adapted to a Swedish context (ICN 2017). They are four core areas which are; 1. Nurses and people, 2. Nurses and practice, 3. Nurses and the profession, and 4. Nurses and co-workers (ICN 2012). According to the first area, nurses need to work for and advocate that the human rights of the patients are respected. It is also the nurse’s responsibility to provide adequate information adapted to the patient’s needs. The second area of ICN includes the nurse having a responsibility of updating themselves with new research and information (ICN 2012).

One of the nurse’s core competencies are to conduct person centered care. This means that the nurse has the responsibility of making sure that, while caring for the patient, the patient and their relatives’ dignity and integrity is protected. It is also important that the nurse makes sure that the patient, as well as their relatives, feel like they are seen as individuals with their own unique needs, resources, values and expectations. The nurse also has to plan and conduct the patient’s care together with the patient as an active participant, as well as relatives when relevant. The nurse’s role also includes promoting health in the patient in accordance with the patient’s own individual definition of health. It is also important to make sure that the patient has continuity in their care (Svensk Sjuksköterskeförening 2017).

Being diagnosed with T1DM means a lifetime of self-care, as in daily monitoring blood glucose levels and daily insulin therapy as well (Malone et al. 2005). Most patients with T1DM can maintain their autonomy by managing their own treatment, (Hakkarainen et al. 2017). It is therefore essential that the patient is well informed of their disease and treatment plan. Nurses need to be aware of this and support the patient in their self-management and encourage them to maintain their autonomy as far as possible (Mertig 2012).

2.6 Health
The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1946, p. 2).

World Health Organization’s definition of mental health is “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses in life, can work productively and fruitfully, and is able to make a contribution to his or her community” (World Health Organization 2014).

Social health consists of two different aspects, which are, social support and social adjustment. Social support focuses on the social support that the person receives from the
people around them, while social adaptation looks at the person’s ability to adapt to and interact with their society. Good social health means that the individual fulfils these two aspects in a positive manner (McDowell 2006).

The term ‘psychosocial’ can be defined as the interaction between the individual’s psychological and social features. In terms of health, the social and psychological situation of the patient interacts with and affects one another. This could potentially benefit the individual or lead to the individual experiencing a decline in health (Singh-Manoux 2003).

2.7 The interaction between psychosocial functioning and living with a chronic disease
Living with a chronic disease makes the patient more likely to experience psychosocial adversity, which can then lead to a negative impact on the patient’s mental health (d’Emden et al. 2018). Research does in fact show that living with a chronic disease impacts the patient’s mental health, which includes patients with diabetes mellitus (Rokne 2013). How a person experiences a chronic condition is influenced by many different factors and not just the disease itself. Age, sex, race, strategies of coping, and recent experiences are individual factors. Relationships, psychosocial support, financial status and life goals also influence the individual’s experience. All changes in life cause stress to some extent. The amount of stress the individual experiences due to a health condition depends on the different threats the condition has on the individual, for example; threats regarding physical well-being, integrity, autonomy, independence and control. One way this stress can manifest itself is as depression, but it can also lead to anxiety (Harrison et al. 2017).

2.8 Problem statement
T1DM is a chronic disease which is increasing in the global population, which means that nurses will encounter this patient category regularly. As previously established, living with a chronic condition can lead to a higher risk of developing mental health issues. It is therefore important that nurses have the ability to provide adequate information and support to these patients. This is why it is highly relevant to research the psychosocial aspects within T1DM in order to understand how this specific chronic condition may affect these patients’ psychosocial health. This study thereby contributes with new knowledge by highlighting the importance of awareness when it comes to the psychosocial aspects of living with T1DM.

2.9 Aim
The aim of this literature review was to describe how living with type 1 diabetes mellitus may affect the patient’s psychosocial health.
3. Method
A literature review is usually the first step in conducting a study. Studying a review can give readers and researchers options to contribute further if there are any inconsistencies in the analysis. The most influential sources of information in a literature review come from previous research. There are primary sources and secondary sources, primary sources are created by the original author. Secondary sources normally refer to a primary source. The process for a literature review is similar to any other study (Polit & Beck, 2017).

Polit and Beck’s (2017, p. 89) nine step illustration which describes the process of writing a literature review, was used as support in order to carry out this review (see figure 1).

![Flow of tasks in a literature review](image)

**Figure 1.** Flow of tasks in a literature review, quoted from Polit & Beck (2017, p. 89).

When developing this literature review, a problem area within nursing was first established, then the research questions that were going to be the foundation of this literature review were developed. This was the first step for conducting a study according to Polit & Beck (2017). Following the second step, it was then decided which databases were going to be utilised, which in this case were PubMed [Public Medline], CINAHL [Cumulative Index to Nursing and Allied Health Literature] and PsycInfo [Psychological Information Database]. Relevant search terms were also selected. In order to discover relevant articles, these search terms were then used in the previously mentioned databases. The search terms used in PubMed, CINAHL and PsycInfo were “diabetes mellitus, type 1”, “mental health”, and “psychosocial support”. Relevant inclusion and exclusion criteria were established.

**Inclusion criteria:** The studies referenced in this literature review had to be written in English, peer reviewed and published between the 1st of January 2014 to the 25th of January 2019. The articles also had to be based on participants diagnosed with T1DM and adults.
**Exclusion criteria:** Studies focused on participants with diabetes who had other prior diagnoses were excluded. The review could not include previous literature reviews. Studies where it was not possible to distinguishable what type of diabetes the results refer to were excluded.

### 3.1 Search process

Following the **third step** using Polit & Beck’s (2017) nine steps illustration, the search process was initiated. PsycInfo did not have a thesaurus word for “diabetes mellitus, type 1” and therefore had to be searched using free text search. CINAHL, which uses major headings, did not have a major heading called “psychosocial support”, however, it did have a major heading called “support, psychosocial” which was deemed to be equivalent to the corresponding search term used in the other two databases. PubMed used MeSH terms which were applicable. CINAHL and PsycInfo have an advanced search option which were used to search for peer reviewed articles published after 1st of January 2014. However, to confirm that the articles selected were in fact peer reviewed, the authors also manually examined if the articles were peer reviewed. PubMed does not have the option of searching specifically for peer reviewed articles, however, there is an option to limit the search for articles published within the last five years, which was utilised. The searches were conducted on 25/1-19 and are displayed in separate tables which represent each database (see table 1 and table 2).

<table>
<thead>
<tr>
<th>Table 1. CINAHL search results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CINAHL</strong></td>
</tr>
<tr>
<td>S1</td>
</tr>
<tr>
<td>S2</td>
</tr>
<tr>
<td>S3</td>
</tr>
<tr>
<td>S4</td>
</tr>
<tr>
<td>S5</td>
</tr>
<tr>
<td>S6</td>
</tr>
<tr>
<td>Total:</td>
</tr>
</tbody>
</table>

() = internal duplicate within result and selection.
Table 2. PubMed search results

<table>
<thead>
<tr>
<th>PubMed</th>
<th>Results found</th>
<th>Selection 1</th>
<th>Selection 2</th>
<th>Selection 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1</td>
<td>Diabetes mellitus, type 1</td>
<td>10,958</td>
<td></td>
<td></td>
</tr>
<tr>
<td>S2</td>
<td>Mental health</td>
<td>10,085</td>
<td></td>
<td></td>
</tr>
<tr>
<td>S3</td>
<td>Social support</td>
<td>14,249</td>
<td></td>
<td></td>
</tr>
<tr>
<td>S4</td>
<td>S1 AND S2</td>
<td>24</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>S5</td>
<td>S1 AND S3</td>
<td>98</td>
<td>13 ((2))</td>
<td>7</td>
</tr>
<tr>
<td>S6</td>
<td>S1, S2 AND S3</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Total:</td>
<td></td>
<td>17</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

((i)) = external duplicate within result and selection

3.2 Selection 1
Following step four by Polit and Beck (2017), relevant sources were identified by screening the titles of the articles from the search results to quickly determine whether the source was relevant. To acquire a better understanding of the articles, the abstracts were read in order to further eliminate any irrelevant articles. Throughout the two previously described steps, the articles were screened using the inclusion and exclusion criteria previously set up.

While searching for articles in PsycInfo, it was discovered that all relevant articles chosen were duplicates from CINAHL and PubMed. Therefore, PsycInfo was excluded as a search database since there were no unique and relevant articles found in said database. After conducting the search, 502 articles were screened. Articles that were not relevant to the aim of the study and review articles were excluded as well as articles that met the exclusion criteria or did not meet the inclusion criteria. From selection 1, 34 articles remained, 17 from CINAHL and 17 from PubMed. There were two internal duplicates from CINAHL and two external duplicates from PubMed. They were excluded, which is presented in table 1.

3.3 Selection 2
In accordance with step five by Polit and Beck (2017), the 34 full articles were browsed in order to further determine whether they were suitable in regard to the aim of this literature review. Following with step six by Polit and Beck (2017), articles that at this stage turned out to not be applicable to the aim were excluded. Articles that after analysis, did not meet the inclusion/exclusion criteria were also eliminated, for example, when it was not possible to distinguish if the patients had T1DM or T2DM. After analyzing the articles, 15 articles remained, seven from CINAHL and eight from PubMed.

3.4 Selection 3
The 15 articles remaining were either qualitative or quantitative studies. In order to evaluate the reliability and trustworthiness of the articles, according to step seven by Polit and Beck (2017), two guides for critiquing were utilised. “Guide to an Overall Critique of a Qualitative
Research Report” (Polit & Beck 2017, p.102-105) was used as a foundation for all the qualitative articles and “Guide to an Overall Critique of a Quantitative Research Report” (Polit & Beck 2017, p.106-109) was applied to all the quantitative articles. After a thorough analysis, three more articles were excluded since they were discovered to be reviews. Twelve articles remained, seven from CINAHL and five from PubMed. Six articles were qualitative, and six articles were quantitative.

3.5 Data analysis
All the articles were printed out so that physical copies could be highlighted using differently coloured markers. In accordance with step eight by Polit and Beck (2017), the articles were read multiple times by both authors separately, while reading, relevant data was extracted. This was carried out inductively. The data was then discussed between the authors to confirm relevance. By analysing the results of the articles, mutual key areas were found and developed into themes. Five themes were established and represented by a specific colour of a highlighter. By using highlighters, the relevant data was highlighted and then organized according to colour. Following the ninth step by Polit and Beck (2017), the data was processed into results. The five previously developed themes were later condensed into two more appropriate themes and seven subthemes, which were more relevant to the aim of the study.

3.6 Research ethics
There are certain rules and regulation regarding ethics when conducting research (CODEX, n.d.). To ensure that this study had been conducted ethically, all the articles used in this study were peer reviewed and approved by a board of ethics. The articles were also critiqued according to Polit and Beck (2017). How the articles had conducted the study and protected the participants were two of the ethical key points in Polit and Beck’s guides to critiquing qualitative and quantitative studies and were specifically taken into consideration when critiquing the articles. The Declaration of Helsinki (Declaration of Helsinki, World Medical Association, 1964) has determined guidelines for ethical research on human subjects. One of the key points was 24§, which states that the researchers needs to protect the participants’ privacy and confidentiality of the information the participant provided. Another key point was 25§, that the participants had consented to the study and been informed that participation was voluntarily for the duration of the study (World Medical Association, 1964). The articles used in the results of this study had to take these ethical aspects into consideration.

Each article was also analysed individually by the authors who put their potential preconceptions aside to examine the articles objectively. There was no plagiarism, falsification or fabrication when conducting the study. An article matrix was created to concisely display the material that was used to comprise the results of the study (see appendix 1).
4. Results
The aim of this literature review was to describe how living with type 1 diabetes mellitus may affect the patient’s psychosocial health. The results of this literature review were based on twelve articles, six of which were qualitative and six were quantitative. Two main themes and seven subthemes were then developed based on these results. The first main theme was ‘Living with T1DM affected the patient’s psychosocial health’, with the subthemes ‘Women were more negatively affected compared to men’, ‘Emotions associated with self-management of T1DM were guilt, control, fear and stress’, ‘Patients altered their behaviour to avoid hypoglycaemic episodes in public’, ‘Patients experienced diabetes distress related to their work’, and ‘There was a perceived stigmatisation of the patients and their disease’. The second main theme was ‘Psychosocial support when living with T1DM was important’ with the subthemes ‘Peer support within the diabetes community played a significant positive role’ and ‘Psychosocial support from healthcare professionals was important’.

4.1 Living with T1DM affected the patient’s psychosocial health
Patients with T1DM described being mentally affected by their disease (Clarke et al. 2018; d’Emden et al. 2016; Hakkarainen et al. 2016; Handley et al. 2015). Some patients expressed that they had previously been diagnosed with depression (Clarke et al. 2018) or disclosed having poor quality of life (d’Emden et al. 2016). Those who struggled with accepting their T1DM diagnosis were also shown to suffer from symptoms of depression (Hakkarainen et al. 2016). Overall wellness and quality of life was perceived as higher in patients between 18-30 years compared to patients over the age of 30 (Vallis et al. 2017). Suicidal ideation was present among patients with T1DM (Handley et al. 2015). Highly perceived physical health among those with T1DM correlated with a lower level of suicidal ideation (Rassart et al. 2015). However, even patients with T1DM who had not been diagnosed with any mental health issues, reported emotional struggles related to their chronic disease. Examples of these struggles were feelings of shame, guilt, fear, lack of motivation, as well as feeling alone, helpless and hopeless (Clarke et al. 2018). Patients also reported being troubled by harmful eating behaviour. Many were also troubled with compensatory behaviour. Examples of this was excessive exercise, binge eating or insulin restriction (d’Emden et al. 2016).

4.1.1 Women were more negatively affected compared to men
There were discrepancies between men and women when it came to psychological issues of living with T1DM. Women were overrepresented in these issues (d’Emden et al. 2016; Rassart et al. 2015). While women generally felt that they had more social support than men, women diagnosed with T1DM had markedly elevated psychological stress (d’Emden et al. 2016). Women also had a lower perception of personal control (Rassart et al. 2015). They were also more prone to be troubled by eating disorders (d’Emden et al. 2016) and to suffer from fear of hypoglycaemia (Anarte et al. 2014).

4.1.2 Emotions associated with self-management of T1DM were guilt, control, fear and stress
Guilt was a feeling that occurred with some patients. When blood glucose levels were elevated as a consequence of their behaviour they would feel guilty and ashamed. Some would feel guilty after eating certain items, for example chocolate. The term ‘control’ had different definitions for different patients. Some felt being in control meant monitoring their T1DM and blood glucose levels. A sense of control was felt when they would follow blood glucose levels despite what it read. Others would feel in control when their blood glucose level was within a healthy range. For some, the sense of being in control would make them feel like they were minimizing the risk of future diabetes related complications (Carlton et al. 2017).
Having T1DM could also be a bit of a hassle and perceived as a loss of freedom. It was mostly referred to when going to appointments with health care professionals, although some would describe monitoring blood glucose levels as a hassle and/or carrying medicine and blood glucose monitoring equipment (Carlton et al. 2017).

Fear, worry and anxiety were all connected to different factors of T1DM and self-management. Fears were particularly associated with insulin usage. Some felt uncertain whether they were doing things correctly, which resulted in a constant level of worry (Carlton, et al. 2017). Another worry affecting many diagnosed with T1DM was how T1DM and the implications of having the disease would affect them in the future (Carlton et al. 2017; Vallis et al. 2017). Patients’ who had a higher perception of consequences also displayed elevated issues related to treatment, food, social support, as well as emotional issues. This particular concern was connected to how much information, or lack thereof, the patient had received on how the disease would affect the body. Hence, why those lacking information would feel anxious about diabetes related complications in the future. In contrast, others thought they had received too much information, which did not alleviate their worries or fears (Rassart et al. 2015).

Stress was common among patients (Carlton et al. 2017; d’Emden et al. 2016; Hakkarainen et al. 2016; Rassart et al. 2015; Vallis et al. 2017) but had different meaning to different patients and was partially related to having T1DM (Carlton et al. 2017). Younger adults did experience a greater level of stress, anxiety and a feeling of being overwhelmed in comparison to adults (Vallis et al. 2017). Managing T1DM could be stressful and some considered going to diabetes related appointments as a stressful event (Carlton et al. 2017). There was also an association between stress and level of HbA1c. Of those who had a stable HbA1c, some reported they repeatedly felt stressed, while those with an unstable HbA1c reported a higher prevalence of regular stress (Hakkarainen et al. 2016). Those who experienced a high level of stress were shown to also have an increased risk of suicidal ideation (Handley et al. 2015).

4.1.3 Patients altered their behaviour to avoid hypoglycaemic episodes in public
Restrictions was associated with T1DM, particularly with those who struggled with hypoglycaemia unawareness. Most patients with T1DM had recalled at least one instance where they could not detect the symptoms of hypoglycaemia, which had resulted in a traumatic experience. Due to these experiences, many patients had restricted and changed their lifestyles in order to decrease the risk of having future hypoglycaemic episodes. Examples of these restrictions included spending less time away from home due to the risk of people not knowing how to act in case of a hypoglycaemic episode, or due to a feeling of lack of control or risk of feeling embarrassed. When leaving home, even for short amounts of time, it demanded extensive amounts of planning for some patients with T1DM, which led to them not feeling like they were able to have any spontaneity in their lives. They also reported restricting physical hobbies, or giving up competitive sports, due to the increased risk of hypoglycaemia. One person described it as “a big loss, a massive loss for me” (Rankin et al. 2014a, p.184). On the other side of the spectrum, some patients with T1DM who had trouble recognizing symptoms of hypoglycaemia elected to downplay or not acknowledge their diabetes due to them not wanting it to disrupt their daily lives (Rankin et al. 2014a).

Diabetes related stress was commonly experienced by patients with T1DM (d’Emden et al. 2016; Rassart et al. 2015) and there was a strong correlation between incidents with hypoglycaemia and diabetes related distress (d’Emden et al. 2016; Hakkarainen et al. 2016). A common way to avoid getting hypoglycaemic was utilising food preventively as a way of increasing blood glucose levels. Even though increased blood glucose levels were potentially going to lead to complications in the future, the thought of being embarrassed at work due to hypoglycaemia was prioritised. In rare cases, living with hypoglycaemia unawareness affected
the lives of patients with T1DM to the extent that they would quit their jobs, retire early, or not pursue employment (Rankin et al. 2014a). The main risk of suffering from fear of hypoglycaemia was due to a lack of support from friends, work, or healthcare providers. Among patients with T1DM who were under the age of 40, the main risk factor for suffering fear of hypoglycaemia was a lack of support from their friends, while the most significant risk factors among those over the age of 40 were a lack of support from their family as well as needing help in the case of a hypoglycaemic event in the past (Anarte et al. 2014). Being unable to detect signs of hypoglycaemia affected the lives of patients with T1DM negatively. Some would feel devastated having their driver's license withdrawn, or being removed from, for example, military services. Some described having to entrust friends and family to identify symptoms of hypoglycaemia. Others would feel anxious and scared of not being near family or friends while some reported the opposite of not wanting to rely on friends and family by fear of become someone's burden. Many felt appreciation having family acknowledging signs of hypoglycaemia (Rankin et al. 2014a).

4.1.4 Patients experienced diabetes distress related to their work
Approximately half of the patients with T1DM reported experiencing diabetes distress related to their work occasionally, while some reported experiencing this kind of stress regularly. Those who felt that their work environment lacked in different physical or psychosocial aspects were more likely to experience diabetes distress. Work related diabetes distress was shown to be significantly lower among those with a higher education. A slight majority of patients who reported keeping their blood glucose elevated at work also expressed that they often felt diabetes distress related to their work. Patients who struggled with coming to terms with their T1DM were also more likely to experience diabetes distress related to their work (Hakkarainen et al. 2016). Patients reported that they chose not to disclose the fact that they had T1DM to employers or employees because they did not want their disease to control their lives or prevent them from working (Rankin et al. 2014a).

4.1.5 There was a perceived stigmatisation of the patients and their disease
Many patients with T1DM recognized a stigma associated with diabetes (Carlton et al. 2017). Most thought the stigmatisation was connected to treating and monitoring the disease in public, mostly due to the general negative association with needles. They were mostly concerned about how they were perceived by others, specifically how they perceived by children (Carlton et al. 2017). A significant amount noted there was discrimination against those living T1DM (Vallis et al. 2017). Some considered diabetes being unfavourably portrayed by the media, this was mostly referring to how poor diet and excessive weight was linked to diabetes, specifically T2DM (Carlton et al. 2017). Some believed there was a misunderstanding among the general public concerning the relationship between weight, poor diet and food-related decisions among those who had diabetes, including T1DM. This was also noted to be an issue when they would attend follow-ups by healthcare professionals (Carlton et al. 2017). Many patients reported that they limited the amount of information that they chose to divulge to certain people due to a fear of stigmatisation (Rankin et al. 2014b).

4.2 Psychosocial support when living with T1DM was important
A sense of support affected the management of T1DM positively (Anarte 2014; Carlton, et al. 2017; Handley et al. 2015; Rassart et al. 2015). Patients had at some point asked for and gotten support from their friends, family, colleagues, or significant other (Rankin et al. 2014b; Vallis et al. 2017). Psychosocial health increased in patients with T1DM when receiving education one on one as well as in groups (Vallis et al. 2017). Different forms of support were preferred from person to person (Carlton et al. 2017; Rankin et al. 2014b). Some wanted no or barely any
involvement from others, while some wanted help with practical aspects (Rankin et al. 2014b), for example help with glucose monitoring and medication. Others reported that they just wanted to have someone to talk to (Carlton et al. 2017), while some wanted help by having someone who would keep them accountable and continually check in with them (Rankin et al. 2014b). Living with T1DM and having a partner decreased the risk for suicidal ideation (Handley et al. 2015). Although for some patients with T1DM, too much support lead to agitation and sometimes would make the patient feel both humiliated and like a child (Rankin et al. 2014a). It was much more common among those who were diagnosed at an early age to continue to seek support from their parents compared to those who were diagnosed as adults, who were instead more likely to share less information with their parents regarding their disease. However, some who reported receiving parental support felt that this support was not always helpful due to the parents giving advice that were considered to be outdated (Rankin et al. 2014b). Young adults also expressed feeling greater support from those who were close compared to older adults who disclosed having less people around them who were supportive (Vallis et al. 2017).

Even though many patients with T1DM did receive various amounts of help and support from others, they did also take accountability and recognized that in the end they had the main responsibility of taking care of their diabetes (Rankin et al. 2014b).

4.2.1 Peer support within the diabetes community played a significant positive role
Patients with T1DM reported that being able to share their stories with the diabetes online community, as well as taking part of other people’s experiences regarding living with T1D, made them feel empowered and less alone (Hilliard et al. 2015). Young adults sought information about T1DM online and were also prone to joining motivational groups (Vallis et al. 2017). Patients with T1DM who socialized with their peers were considerably less likely to experience higher levels of T1DM related isolation, symptoms of depression, as well as anxiety (Saylor et al. 2018). They also reported forming new, supportive friendships with their peers (Hilliard et al. 2015).

“The encouragement and validation that I received from a community that can say, ‘me too’ is as important to my health as the insulin that I take... Finding a community of people who get it, who have the same literal highs and lows as I do, has helped me and thousands of others who live with diabetes and feel scared and isolated feel empowered and connected....peer to peer support fosters resilience and confidence. It turns our shared vulnerability into empowerment, and we can gain strength from the places we normally feel weak.”

(Hilliard et al. 2015, p. 264).

Patients with T1DM saw their peers as trustworthy sources. Examples of this being that they could give recommendations concerning new diabetes related technology and practical advice for concealing or holding devices in their clothing (Hilliard et al. 2015).

4.2.2 Psychosocial support from healthcare professionals was important
A need for healthcare professionals to be more supportive was mentioned (Carlton et al. 2017). It was reported that when healthcare professionals did inquire regarding the patient’s hypoglycaemia unawareness it was mainly from a medical point of view, as opposed to looking at the emotional aspects of living with it (Rankin et al. 2014a). There was also no mentioning of healthcare professionals ever encouraging their patients to talk about the psychosocial effects of living with T1DM and how to seek support (Rankin et al. 2014a). The support that patients with T1DM wanted from healthcare professionals ranged from regularly receiving feedback,
having a person to contact in case they had any questions, to receiving help with motivation when it came to diabetes management (Carlton et al. 2017). Patients reported that in order to maintain motivation, an important factor was keeping regular contact with healthcare professionals. Patients also reported that in order to be able to accept their diagnosis and then be able to comply with the current treatment it was very important that they possessed relevant information and understanding about their disease (Carlton et al. 2017). Some patients disclosed emotional issues related to living with T1DM and that healthcare professionals did not take this seriously and instead acted dismissively when the issue was raised by the patient (Clarke et al. 2018).

“I was just told that it was all in your head. [...] no one could recognize that diabetes affects mental health and mental health affects diabetes - it's like a dog chasing its tail”

(Clarke et al. 2018, p. 671).
5. Discussion

The aim of this study was to describe how living with type 1 diabetes mellitus may affect the patient’s psychosocial health. Two main themes and seven subthemes were then developed based on these results.

5.1 The psychosocial aspects of living with T1DM

The results showed that living with T1DM and issues with mental health were connected. (Clarke et al. 2018; d’Emden et al. 2016; Hakkarainen et al. 2016; Handley et al. 2015). This is further supported by other research, which also came to the conclusion that living with T1DM increases the risk of depression (Gemeay et al, 2015). The study by Rassart et al. (2015) advocates the importance of screening and treating depression, due to the high prevalence of depression within the T1DM population (Rassart et al. 2015).

Another study came to a somewhat different conclusion. Patients expressed that they felt restricted due to their diabetes. However, it was also mentioned by some that even though the disease came with certain limitations, they still felt that the diabetes did not define them as a person and that they had other things to offer (Abdoli et al. 2017).

One of the findings in the result was linked to eating behavior. There was a significant amount of those diagnosed with T1DM who struggled with this (d’Emden et al. 2016). An article by Staite et al. (2018) confirms that eating disorders are one of the most common comorbidities when living with T1DM, and particularly younger patients with T1DM are troubled by this.

5.1.1 Women with T1DM

Women were overrepresented regarding emotional issues (d’Emden et al. 2016; Rassart et al. 2015) and were also more prone to fear hypoglycemia (Anarte et al. 2014) and eating disorders (d’Emden et al. 2016). A study by Chelvanayagam and James (2018) suggests that 20% of women with T1DM have an eating disorder. Eating disorders and T1DM can potentially lead to serious complications due to hyperglycaemia. The study advocates that nurses need to be aware that all patients with T1DM can develop an eating disorder and that younger females are overrepresented (Chelvanayagam & James, 2018).

5.1.2 Emotions associated with self-management of T1DM

The results found that some aspects of living with T1DM were related to negative feelings. These feelings were associated with guilt, control, restriction and hassle. They were all connected to self-management and the patient’s blood glucose level (Carlton et al. 2017).

Self-management was a huge part of the daily lives of those who were diagnosed with T1DM. Having responsibility over their own treatment could lead to feelings of fear, anxiety and worry about not being able to self-manage correctly (Carlton et al. 2017). On the other hand, another study came to a somewhat contradictory result (Rechenberg et al. 2018). Some felt confidence in their capacity to self-manage their condition. Even though they considered their self-management to be time consuming and an annoyance, they managed to incorporate it into their daily lives to the extent that it was unnoticeable for them. This was considered an achievement. To achieve this, it was important for the patient not to be ashamed of their disease and not to be embarrassed by performing self-management tasks in public. They considered their disease to be normal and felt they could be open about it to their friends and family. They were well-informed about how the disease affects them physically and physiologically and how self-management had an effect on the outcome. When it came to feeling hypo- or hyperglycaemic, they were well-prepared on how to handle these symptoms. Even though they felt confident about their ability to manage their T1DM, they would still worry about the future and how the disease would affect them in the long term. However, they understood and accepted that
potential future complications were a part of living with the disease. Those who had managed to successfully incorporate their T1DM into their daily lives were also reported to function better psychosocially (Rechenberg et al. 2018).

Feeling stressed was considered to be usual for the patients with T1DM (Carlton et al. 2017; d’Emden et al. 2016; Hakkarainen et al. 2016; Rassart et al. 2015; Vallis et al. 2017). How the condition would affect them in the long term and attending diabetes related appointments could cause stress to some extent (Carlton et al. 2017). A different study by Klages et al. (2018) have developed a validated diabetes stress questionnaire [DSQ] which looks at several aspects that may cause stress in patients with T1DM, the aforementioned aspects included (Klages et al. 2018).

5.1.3 Hypoglycaemia and its psychosocial effects
One of the major psychosocial concerns of living with T1DM was related to hypoglycaemia and how it affected the patient’s work situation. A few cases demonstrated how severe the psychosocial aspects could be when it came to patients who had professional careers (Rankin et al. 2014a).

Hypoglycaemia unawareness could drastically affect the personal lives of patients with T1DM as well. One person blamed the end of his marriage on hypoglycaemia and describing getting his life back together by ignoring his hypoglycaemia unawareness, understanding it would affect his health (Rankin et al. 2014a).

Fear of hypoglycaemia affected some of the patients with T1DM and was connected to the amount of hypoglycaemic events that required help within the last six months. Fear of hypoglycaemia lead to elevated anxiety and it would make some delay their sleep on purpose or occasionally avoid attending social events to avoid becoming hypoglycaemic. This behaviour was due to a fear of not receiving necessary help in case of hypoglycaemia. Many would purposively elevate their blood glucose to avoid the risk of having a hypoglycemic episode in public (Hakkarainen et al. 2016; Rankin et al. 2014a). Lacking support from friends, family, work or healthcare providers would increase the risk of fear of hypoglycemia (Anarte et al. 2014).

5.1.4 Psychosocial factors related to work
It was stated that about half of the patients with T1DM had at some point experienced diabetes distress related to their profession (Hakkarainen et al. 2016). Some would not disclose the fact that they had T1D at work (Rankin et al. 2014a). A study conducted by Hakkarainen et al. (2017) confirmed that approximately half of those with T1DM would not disclose their disease to their colleagues. Psychosocial factors were the biggest reason for them to disclose their disease. For example, they were more prone to reveal their condition if they were receiving social support from their colleagues (Hakkarainen et al. 2017). Patients would purposely elevate their blood glucose level at work in order to avoid the embarrassment of becoming hypoglycaemic (Hakkarainen et al. 2016; Rankin et al. 2014a). Loerbroks et al. (2018) have studied the connection between different psychosocial work factors and how they impact the patient’s diabetes self-management at work. It was found that factors such as a high workload, a lack in job control, the physical and social work environment, as well as the specific job demands, all played a part in whether the patients felt that they could adequately carry out their diabetes self-management. Aspects related to diabetes self-management that were suffering as a result of the aforementioned factors were control of the blood glucose level (Loerbroks et al. 2018).
5.1.5 Perceived stigmatisation of diabetes

The results showed that there was stigma associated with diabetes, since many with T1DM, for example, thought that needles had negative connotations among the general public (Vallis et al. 2017). Some also thought that diabetes in general was unfavourably portrayed by the media (Carlton et al. 2017). Both these aspects were confirmed in a study made by Browne et al. (2014). According to Rechenberg et al. (2018), many did not want to disclose their T1D to other people to avoid being judged.

5.2 The value of psychosocial support when living with T1DM

The amount of support from friends and family members varied greatly between patients (Carlton et al. 2017; Rankin et al. 2014b). It affected the management of T1DM in a positive way (Carlton et al. 2017). Participants in another study expressed that they indeed did feel positively supported by both their family and friends (Abdoli et al. 2017). Still, it is important for friends and family to understand that helping the patients with their diabetes management can also be perceived as overly helpful and lead to resentment (Rankin et al. 2014a).

There was also a correlation between the patients HbA1c and the prevalence of emotional issues, as well as issues when it came to social support (Rassart et al. 2015).

5.2.1 The role of peer support within the diabetes community

The results presented many benefits with peer support when living with a chronic condition. Levels of isolation, depression and anxiety related to T1DM were lower with those who sought peer support (Saylor et al. 2018). They also felt empowered, by their online peers, to take charge of their T1DM (Hilliard et al. 2015). A study made by Abdoli et al. (2017) confirmed that patients with T1DM benefit from having contact with their peers, both in person and online.

Another study by Gabbaron et al. (2018) found that those who are active in diabetes online communities were interested in acquiring diabetes related information, for example new research and innovations, on social media platforms. They also examined closed groups within the diabetes online communities and found that the main topics of the groups were mostly related to self-management of T1DM. They felt free to exchange personal aspects related to T1DM and self-management in these closed groups. The study concluded that social media could be used as a platform for health-promotion intervention to target this specific patient category. Although this does not come without limitations, as there are differences in access to technology and differences in culture. Also, information on social media is easily misinterpreted and has the ability to spread quickly (Gabbaron et al. 2018).

5.2.2 The importance of support from healthcare professionals

There were issues regarding the relationship between healthcare professionals and patients with T1DM. The main issue was that healthcare professionals did not acknowledge the emotional aspects of living with T1DM (Rankin et al. 2014a). Therefore they could not provide adequate support (Carlton et al. 2017). A study by Greene (2009) found that it is important to address the patient’s attitudes and feelings towards the disease. As a nurse it is imperative to find a balance between encouraging the patient’s diabetes care but at the same time making sure that the they are not overwhelmed (Greene 2009).

Psychosocial factors should be taken into consideration by healthcare professionals when working with patients with T1DM. There are many psychosocial constraints, such as others’ perceptions, stigma, and the possibility of conflict with friends and family. The constraints can potentially prevent the patient from achieving their glycaemic goals (Hilliard et al. 2018).

In the study it was described that an appointment for diabetes control could cause stress. This was mainly referred to when diabetes self-management and the patient was concerned about being scolded for not managing their blood glucose levels properly (Carlton et al. 2017).
Patients disclosed anxiety about future complications related to diabetes and would think that they received either too much information by healthcare professionals or that they were lacking information (Carlton et al. 2017). The results also found that healthcare professionals did not encourage patients to discuss the psychosocial effects of living with T1DM or how they could receive support (Rankin et al. 2014a). Some patients even experienced that healthcare professionals did not take the emotional aspects of living with T1DM seriously and would dismiss the concerns raised by the patient (Clarke et al. 2018). A study conducted by Mohn et al. (2015) came to the conclusion that patients who experienced a lack of support from healthcare professionals also experienced a higher amount of distress (Mohn et al. 2015). Some patients reported that they did not mention their concerns regarding hypoglycaemia unawareness to healthcare professionals (Rankin et al. 2014a). This was due to a desire to make the issue seem less significant since they were afraid of losing their jobs, or feeling like they would need to give up hobbies. Another reason some decided not to disclose this concern was that they thought that there is nothing that can be done to treat hypoglycaemia unawareness (Rankin et al. 2014a).

To patients with T1DM, it was important that healthcare professionals did not just see the disease, but also the person living with the disease and their individual needs. Patients also felt a need for continuity in their care and the healthcare professionals that they meet (Greene 2009). This need is acknowledged in the Swedish Nursing Association’s description of the nurse’s core competencies, where one of the main competencies include person centered care (Svensk Sjuksköterskeförening 2017).

5.3 Method discussion

The study followed Polit and Beck’s (2017) nine steps for conducting a literature review to affirm that the study was conducted appropriately. The way it was conducted was described thoroughly to ensure its replicability and validity. The databases, CINAHL and PubMed, were chosen since they were deemed relevant to the area of nursing. PsycInfo was added as a database to gain more resources regarding the psychological aspect. It was later in the study removed as a database since all articles found in PsycInfo were duplicates from CINAHL and PubMed. The search terms chosen were ‘diabetes mellitus, type 1’, ‘mental health’ and ‘psychosocial support’. ‘diabetes mellitus, type 1’ was chosen as a search term as it was the disease in question for this study. ‘Mental health’ was selected as a search term since psychosocial aspects are closely connected to mental health and vice versa. ‘Psychosocial support’ was chosen as a search term since the term ‘psychosocial’ was part of the aim of the study, and support is an important aspect of nursing. All the searches used the MeSH term/heading ‘diabetes mellitus, type 1’ combined with the chosen search term with the Boolean phrase ‘AND’ to maximize relevance. The word ‘psychosocial support’ did not exist as heading for CINAHL and therefore ‘support psychosocial’ had to be used. It would have been preferred to use the exact same MeSH term/headings on all the searches for all the databases as it would have been a strength for the study.

The inclusion criteria were that the articles used in this study had to be peer reviewed and published between the 1st of January 2014 to the 25th of January 2019. Only including peer reviewed articles ensures the quality of the sources that were used. A five year interwall for the articles were chosen to ensure that the research was up-to-date. The articles had to be based on patients with T1DM and they had to be based on an adult population. The articles had to be published in English.

One of the exclusion criteria set up was that the studies could not focus on those with T1DM who had other prior diagnoses. This was because if the patients had any other diagnoses it may have affected the results. Literature reviews were also excluded. If it was not possible to
distinguish what type of diabetes the study was focused on, that study was also excluded. This was also because it would possibly affect the result.

All the articles chosen were critiqued according to Polit and Beck (2017) to ensure they were all of high academic standard. Six of the articles were qualitative and six were quantitative. A combination of both qualitative as well as quantitative data provides a more nuanced perspective. The limits of one type of data is then balanced out by the strengths of the other data. This was deemed as a strength for the study. One article was from Spain, four from the United Kingdom, three from Australia, one from Finland, two from the United States of America and one from Belgium. All the articles were from first world countries, which may limit the study since it may not be applicable on a global perspective as the healthcare systems and diabetes care varies globally. Although, it can also be seen as a strength for the study since the countries in question are similar to Sweden, and is therefore transferable on Sweden and other first world countries.

5.4 Clinical implications
Living with a chronic condition that also potentially causes future complications, puts a heavy demand on the patient. It can result in long term psychological impact, such as mental health issues.

The results of this study could be utilised to educate nurses on the importance of providing relevant psychosocial care. Legg (2011) defines psychosocial care as taking the patients cultural, spiritual, psychological and social needs into account.

Providing relevant psychosocial care would benefit the patient’s mental health. This would then reduce the amount of hospital admissions and time spent in hospitals that is related to psychosocial issues. From a financial perspective, it would also benefit the hospital as it would lower the costs of these admissions. Instead of just treating the disease, nurses need to have a holistic approach and care for the entire individual, both on a somatic and psychosocial level. This is not only applicable on patients with T1DM, but on any patient living with a chronic disease as various psychosocial aspects are most likely going to affect the patient’s health at some stage. The results of this study could therefore be used to educate nurses on the importance of taking the psychosocial aspects of living with T1DM seriously.

5.5 Further research
The results showed that healthcare professionals seem to lack an understanding of how these patients are affected psychosocially and how important these aspects are for the patient’s general health. More research is needed to develop a further understanding about these psychosocial aspects. An example of further research could consist of exploring the knowledge and attitudes of healthcare professionals regarding the psychosocial effects of living with T1DM. A study of the general public could also be conducted to explore how patients with T1DM are perceived by others. These results could then confirm whether the patients’ perceptions regarding how they are viewed by other people are in fact correct.

5.6 Conclusion
Being diagnosed with T1DM requires a lot of self-management, which is a concern since those with T1DM felt like they could not perform their self-management in public or disclose their disease to friends or work colleagues. This could potentially affect their health, and potentially lead to short and long term complications. The concern regarding how others perceive them does not only lead to potential health consequences but also affect their self-esteem and their mental health.
As a relative it is important to find balance in the support that they provide. There is a difference between being supportive and being overly supportive.

Hypoglycaemia unawareness can impact the lives of those who struggle with this issue, healthcare providers need to be aware that this can affect the patient on a psychosocial level. Healthcare providers, specifically those who work close to patients with T1DM, should be able to recommend different opportunities for their patients to connect with their peers.
6. References:

* Article is used in results


### Appendix 1. Article Matrix

<table>
<thead>
<tr>
<th>Author, year and country</th>
<th>Aim</th>
<th>Method</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anarte, et al. 2014 Spain</td>
<td>To identify the risk factors for fear of hypoglycemia (FH) in DM I patients by applying the FH-15 scale to detect patients with FH and then analyzing the association of clinical and sociodemographic variables.</td>
<td>A qualitative study using structured interviews. Purposive sampling. 250 participants. Dropout rate: 21.</td>
<td>Risk factors for FH were found to be age, need of help when hypoglycaemic and lack of social support.</td>
</tr>
<tr>
<td>Carlton, et al. 2017 United Kingdom</td>
<td>To describe the development of a questionnaire intended for use to measure the impact of self-management in diabetes.</td>
<td>A qualitative study using semi-structured interviews. Purposive sampling. 32 participants. Dropout rate: 1.</td>
<td>Factors associated with living with T1DM were fear/anxiety, guilt, stigma, control, hassle, stress, feeling supported and freedom.</td>
</tr>
<tr>
<td>Clarke, et al. 2018 Australia</td>
<td>The aim is to gain vital information to inform the design, promotion, and recruitment methods of future studies of psychosocial interventions for young adults with type 1 diabetes.</td>
<td>A qualitative study using in-depth interviews. Convenience sampling. 31 participants. Dropout rate: 0</td>
<td>People with T1DM had an increased vulnerability for mental health problems related to their diabetes. Psychological distress was looked upon as normal regarding diabetes. When receiving psychosocial support, human contact was preferred.</td>
</tr>
<tr>
<td>d’Emden, et al. 2016 Australia</td>
<td>To profile demographic, medical and psychosocial characteristics of young people with diabetes, and to develop a screening tool and care pathway for routine use.</td>
<td>A quantitative questionnaire study. Purposive sampling. 172 participants. Dropout rate: 21.</td>
<td>A need for psychosocial screening was identified. A psychosocial screening tool was developed which assesses diabetes distress, depression, anxiety, well-being, fear of hypoglycaemia,</td>
</tr>
<tr>
<td>Name, et al.</td>
<td>Year</td>
<td>Country</td>
<td>Aim</td>
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<tr>
<td>Hakkarainen, et al.</td>
<td>2016</td>
<td>Finland</td>
<td>To examine work-related diabetes distress among Finnish workers with type 1 diabetes.</td>
</tr>
<tr>
<td>Handley, et al.</td>
<td>2015</td>
<td>Australia</td>
<td>To examine the prevalence and correlates of suicidal ideation (SI) in a community-based sample of adults with type 1 or type 2 diabetes.</td>
</tr>
<tr>
<td>Hilliard, et al.</td>
<td>2015</td>
<td>United States of America</td>
<td>The aim is to introduce readers to the platforms on which Diabetes Online Community (DOC) participants interacts, to discuss reasons for and risks associated with diabetes-related online activity, and to review research related to the potential impact for DOC participation on diabetes outcomes.</td>
</tr>
<tr>
<td>Rankin, et al.</td>
<td>To explore the experiences of people who have hypoglycaemia unawareness and its impact on their everyday lives.</td>
<td>A qualitative study using in-depth interviews, with an inductive approach. Purposive sampling. 38 participants. Dropout rate: not disclosed</td>
<td>Lack of hypoglycaemia awareness can affect the patient’s relationships partly due to being dependent on others, but also due to behavioural changes when hypoglycaemic.</td>
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<tr>
<td>Rankin, et al.</td>
<td>To explore patients’ experiences of, views about and need for, social support after attending a structured education programme for type 1 diabetes.</td>
<td>A qualitative study using in-depth interviews, with an inductive approach. Purposive sampling. 30 participants. Dropout rate: not disclosed</td>
<td>Patients have very different preferences when it comes to how much social support and involvement they want from others. According to the study, parents may possess outdated knowledge about diabetes, which can affect their ability to provide adequate social support.</td>
</tr>
<tr>
<td>Rassart, et al.</td>
<td>The aim of the study was to examine the longitudinal interplay of depressive symptoms, diabetes specific perceptions and distress, and glycaemic control in emerging adults with Type 1 diabetes</td>
<td>A longitudinal quantitative survey study. Randomized sampling. 500 participants. Dropout rate: 336</td>
<td>The study concluded that if the participants had more understanding and feeling of control about their disease, it would lead to a decrease in complications five years later.</td>
</tr>
<tr>
<td>Saylor, et al.</td>
<td>The purpose of the study is to examine the characteristics and health outcomes of college students with type 1 diabetes mellitus (T1DM) as it relates to memberships in a local university-based diabetes student organization.</td>
<td>A quantitative survey study. Purposive sampling. 532 participants. Dropout rate: 161</td>
<td>Students who were members of a student-led diabetes organization were reported to be less likely to have increased depressive symptoms, isolation, and anxiety related to diabetes.</td>
</tr>
<tr>
<td>Vallis, et al.</td>
<td>To compare clinical, psychological, education and social variables in emerging adults (aged 18-30 years) with Type 1 diabetes with their adult counterparts aged &gt;30 years.</td>
<td>A quantitative survey study. Purposive sampling. 8 596 participants. Dropout rate: not disclosed.</td>
<td>While the emerging adults were reported to have a higher quality of life, they were also the group who reported a higher prevalence of diabetes distress compared to the adult counterparts.</td>
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</table>